
Make the Stillborn Baby and the Loss Real for the Siblings: Parents' Advice on How the Siblings of a Stillborn Baby Can Be Supported

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ABSTRACT

This study aimed to investigate parents' advice to other parents on the basis of their own experiences of siblings' taking leave of a stillborn sister or brother. The study was a Web questionnaire study of 411 parents. The thematic content analysis resulted in two categories: "Make the stillborn baby and the loss real for the siblings" and "Take the siblings' resources and prerequisites into account." Parents' advised that siblings should see and hold the stillborn baby and, thus, be invited and included into the leave-taking process with respect to the siblings' feelings, resources, and prerequisites. Based on these findings, professional caregivers can usefully be proactive in their approach to facilitate and encourage the involvement of siblings.

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When a baby is stillborn, it is a tragic event not only for the parents but also for older siblings who are waiting for their little sister or brother. The death of a child imposes strains on parents and siblings in a family (de Montigny, Beaudet, & Dumas, 1999;

Dyregrov, 1989; Frøen et al., 2011; Wilson, 2001). The loss of a sibling has been described as similar to the loss of a parent, but the consequences are not as obvious or long-lasting (Brent, Moritz, Bridge, Perper, & Cannobio, 1996; Dyregrov & Dyregrov, 2005; Hogan & Greenfield, 1991).

When it comes to facilitating the grieving process for a child, communication between parents and the child is very important (Black, 2005; Dyregrov,

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1989; Dyregrov & Dyregrov, 2008; Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004). It has been assumed previously that understanding death is the way to recover from bereavement. To involve siblings after stillbirth is therefore recommended because it enables them to understand what happened in the family (Dyregrov, 1989). Siblings should be encouraged to see and hold the stillborn baby (Black, 1996; Wilson, 2001). Siblings often need guidance and support in the leave-taking process (Erlandsson, Avelin, Säflund, Wredling, & Rådestad, 2010). One of the key actions of *The Lancet Stillbirths Series, Stillbirths: The Vision for 2020* (Goldenberg et al., 2011) is to provide bereavement support. However, there is limited knowledge of the parents' perspective on how to support siblings who lost a stillborn brother or sister. The aim of this study was to investigate parents' advice to other parents on the basis of their own experiences of siblings' taking leave of a stillborn sister or brother. A specific aim was to study whether the advice differs between parents who lost their child early or late in pregnancy.

METHODS

Study Design and Data Collection

Data collection was carried out with two Web questionnaires that were available on the Internet between March 27, 2008, and April 1, 2010: one questionnaire for mothers and one for fathers who had experienced a stillbirth. The informants were recruited through the Swedish National Infant Foundation website where written information about the study was given and the questionnaires could be accessed. The foundation is a member organization of the International Stillbirth Alliance and supports parents who have lost a baby before or after birth. Information about the study was also published in advertisements in newspapers and journals during the recruitment phase. The study was approved by the Regional Ethics Committee, Lund, Sweden (reg. no. 467/2006).

Questionnaire

The Web questionnaire consisted of 94 items for mothers and 82 items for fathers, covering biographic information and topics related to the psychological and other support received and the memory of the stillborn baby. The questionnaires were answered anonymously; the Internet Protocol numbers of the computers used by the respondents were not saved and, thus, cannot be associated with individual responses.

Participants

A total of 1,193 parents (1,034 mothers and 159 fathers) answered the questionnaire. Inclusion criteria for this study were that mothers and fathers should have experienced a stillbirth, have older children (i.e., siblings to the stillborn baby), and answered an open question about support to siblings who had lost a stillborn sister or brother. Furthermore, the parents had to have experienced the stillbirth after a gestational period of at least 22 weeks. A total of 411 parents were eventually included in the study, 350 of whom were mothers and 61 fathers.

The participating mothers were born between 1938 and 1988 (median 1971). The stillborn babies were born between 1961 and 2010 (median 2004). Of the mothers, 236 (67.4%) had given birth to one or more children after the birth of the stillborn baby. The fathers were born between 1949 and 1981 (median 1969). Of the fathers, 37 (60.7%) had one or more children after the stillbirth, and 58 (95.1%) were present at the stillbirth. Of the stillborn babies, 46 (11.2%) were born before gestational week 28 was completed, and 365 (88.8%) were born after that week. The mean weight of the babies born before gestational week 28 was 720 g, and the mean weight of the babies born later was 2,950 g. Parental experiences of seeing, holding, and taking the stillborn baby home, as well as collecting mementoes of the stillborn baby and arranging the baby's funeral are presented in Table 1.

Analysis

The parents' answers to the open question, "Did you have older children, siblings to the stillborn baby, at the time of the loss? If yes, please describe

TABLE 1
Parental Experiences of Seeing, Holding, Taking the Stillborn Baby Home, Collecting Mementoes of the Stillborn Baby, and Arranging the Baby's Funeral in Number (*n*) and Percentage (%)

Subject	Mothers (<i>n</i> = 350)	Fathers (<i>n</i> = 61)
Seeing their stillborn baby	<i>n</i> = 328 (93.7%)	<i>n</i> = 60 (98.4%)
Holding their stillborn baby	<i>n</i> = 266 (76.0%)	<i>n</i> = 52 (85.2%)
Collecting mementoes of their stillborn baby	<i>n</i> = 295 (84.3%)	<i>n</i> = 55 (90.7%)
Having photographs of their stillborn baby	<i>n</i> = 310 (88.6%)	<i>n</i> = 58 (95.1%)
Took their stillborn baby home before the funeral	<i>n</i> = 8 (2.3%)	<i>n</i> = 2 (3.3%)
Had a funeral for their stillborn baby	<i>n</i> = 305 (87.1%)	<i>n</i> = 59 (96.7%)

what advice you would give to other parents about siblings' farewell to their little sister or brother" were analyzed qualitatively, according to Malterud's (1993) thematic content analysis.

In the first step of data analysis, all text from the parents' answers (in total 16,000 words), together with corresponding biographic data, was categorized according to whether the stillbirth occurred before or after gestational week 28. To gain a sense of content, all texts were then read through several times. After this naive reading, the sections related to the aim of the study were extracted as meaning units and labelled with one of the codes that emerged during the analytical process. In this step,

we also counted the number of statements in each code inspired by Hildingsson and Thomas (2007). For counting the number of statements, the codes were entered into Microsoft Excel and marked 1 or 0 for the presence or absence of the individual parent (binary index). Codes representing less than 5% are shown in Table 2 but are not discussed in the qualitative description in the findings. By continuously comparing the codes for similarities and differences and after further abstraction, a final recontextualization was done in which a general description in terms of categories and subcategories became possible. In total, two categories, six subcategories, and 36 codes emerged (Table 2).

TABLE 2
Categories, Subcategories, and Codes^a in Percentage (%) and Number (n)

Make the Stillborn Baby and the Loss Real for the Siblings (n = 903)	Take the Siblings' Resources and Prerequisites Into Account (n = 330)
Experience the stillborn baby (n = 335) See/meet (63.6%, n = 213) Hold (19.7%, n = 66) Touch (16.7%, n = 56)	Respect the siblings' feelings (n = 199) See to the needs of siblings (16.6%, n = 33) Participate in siblings' own terms (15.6%, n = 31) Do not coerce (14.6%, n = 29) Mourn together (14.6%, n = 29) Parents ought to show sadness (11.6 %, n = 23) View death as a natural part of life (10.1%, n = 20) Confirm sisterhood/brotherhood (10.1%, n = 20) Relate to the circumstances (3.5%, n = 7) Observe siblings' reactions (1.0%, n = 2) Take the stillborn baby home (1.0%, n = 2) Do not transfer your sadness (1.0%, n = 2) Instill a sense of hope (0.5%, n = 1)
Get siblings involved (n = 329) Participation (48.9%, n = 161) Be present at the funeral (22.2%, n = 73) Give a farewell present to the stillborn in the coffin (17.6%, n = 58) Active part in preparation for the funeral (11.2%, n = 37)	Adapt to the siblings' age (n = 131) Leave-taking (42.0%, n = 55) Depend on siblings' age (35.1%, n = 46) Concretization (8.4%, n = 11) Expressions through play and singing (8.4%, n = 11) Person for own support (3.1%, n = 4) Read books about death (3.1%, n = 4)
Inform and communicate (n = 147) Talk (36.7%, n = 54) Inform (19.0%, n = 28) Provide correct and honest information (19.0%, n = 28) Answer questions (13.6%, n = 20) Provide information when siblings are susceptible (6.1%, n = 9) Enlist the support of health-care staff (2.7%, n = 4) Give support (2.7%, n = 4)	
Create memories (n = 92) Take photographs (63.0%, n = 58) Acknowledge the stillborn baby (22.8%, n = 21) Create your own memories (12.0%, n = 11) Grave/gravestone (2.2%, n = 2)	

^aCodes representing < 5% are shown in Table 2 but are not discussed in the qualitative description in the "Findings" section of this article.

The data were also processed quantitatively. The comprehensive description before and after gestational week 28 were analyzed statistically by using number (*n*), percentage (%), standard deviation (*SD*), and the Mann-Whitney *U* test (*p*). Statistical significance was set at 95%.

FINDINGS

The following two categories were established in connection with the analysis of the parents' advice on how a child that has lost a little brother or sister can be supported: (a) "Make the stillborn baby and the loss real for the siblings" and (b) "Take the siblings' resources and prerequisites into account." In total, six subcategories were connected to these two categories (Table 2).

Make the Stillborn Baby and the Loss Real for the Siblings

This category comprises four subcategories: (a) "Experience the stillborn baby," (b) "Get siblings involved," (c) "Inform and communicate," and (d) "Create memories."

Experience the stillborn baby. This subcategory covered 335 individual pieces of advice about letting siblings hold, touch, or meet their stillborn sister or brother. The advice went from giving siblings the opportunity to see the baby to letting them hold the baby in their arms and touch and stroke the baby. The parents emphasized the importance of making a meeting possible that would render the loss real because it would help the siblings to understand that their little sister or brother has died. The parents thought that a sibling having his or her own image of the stillborn baby would make it easier for a sibling to mourn. The meeting with the stillborn ought to be prepared, though, and it might have to be repeated in order for the siblings to really understand that their little sister or brother is dead. The following comments from parents illustrate their advice to allow siblings to experience the stillborn baby:

The elder sister, who was 3 years old at the time, was counting toes and fingers—a really nice meeting with her little brother. (A mother who had lost her child in gestational week 35)

I think that it was good for her and that it was important to see that the pregnancy had led to this beautiful dead child. It became real for her and less scary than it had been before. (A father who had lost his child in gestational week 35)

Get siblings involved. This subcategory comprised 329 comments about letting siblings participate in the processes surrounding the stillborn baby. By letting siblings participate actively in the funeral and the preparations for it, the unreal could become real for the siblings, according to the parents. In preparations such as dressing the stillborn, decorating the coffin, and choosing the music, the siblings can learn to understand that their little sister or brother has died. The parents' advice was to involve the siblings and let them join in, for them to understand what is happening. Later in life, the parents contended, it can be of importance to the siblings to know that they were present at the funeral, even if they do not have firsthand memories. The following comments illustrate parents' advice in getting the siblings involved in processes surrounding the stillborn baby:

She dressed her little sister, participated in the naming, the funeral, and everything else. (A mother who had lost her child in gestational week 36)

She was with us at the end and lowered the coffin, sang "Twinkle, Twinkle, Little Star" and planted a wild strawberry bush next to the grave. (A mother who had lost her child in gestational week 23)

The parents suggested that siblings meeting with the stillborn baby and helping with the funeral can be prepared by talking with them about what the stillborn looks like and what is going to happen. The siblings should have an adult at their side to support them, a person who can answer questions and take care of them when the parents, because of their own grief, are incapable of giving support. Parents also recommended allowing the siblings to give a farewell present to the stillborn baby in its coffin (e.g., a toy, a teddy bear, a drawing, a letter, or some other personal item), as illustrated in the following comments:

Then she drew a map over Heaven so that her little sister would find her way. (A mother who had lost her child in gestational week 40)

The day before, we had made drawings together and bead necklaces that we were to put into the coffin. My children brought their best teddy bears and put them beside her so that she wouldn't have to lie alone. (A mother who had lost her child in gestational week 39)

Correct and honest information ought to be adapted to the siblings' frame of reference.

Inform and communicate. This subcategory featured 147 statements about providing siblings with information and a chance to talk with their parents. The parents thought it was best to tell siblings early on that their brother or sister died. Correct and honest information ought to be adapted to the siblings' frame of reference, however. Abstract explanations should be avoided, and the word "death" should be used instead of circumlocutions. In order to increase the siblings' understanding and provide an opportunity to ask questions, the information may have to be repeated. The parents thought that one should let the siblings talk when they feel like it and invite conversations where siblings can give expression to their thoughts, questions, and emotions. For example, one parent advised the following:

Always talk with the elder child about how and why it happened; tell the truth. Talk about the dead baby and be available to the siblings when they are ready and when they have questions. (A mother who had lost her child in gestational week 39)

Create memories. This subcategory gathered 92 statements about acknowledging the stillborn baby by letting siblings create, collect, and preserve memories. According to the parents, this approach can be a confirmation that the baby existed and a way for the siblings to retain the dead little sister or brother in their memory as they grow older. Photographs were of special value, especially if the siblings and the stillborn baby were in them together.

Take pictures so that the siblings later get to see evidence that they met their dead brother or sister. (A mother who had lost her child in gestational week 25)

Take the Siblings' Resources and Prerequisites Into Account

This category comprised two subcategories: (a) "Respect the siblings' feelings" and (b) "Adapt to the siblings' age."

Respect the siblings' feelings. This subcategory comprised 199 statements about being aware of the siblings' prerequisites and about being encouraging, but never coercive, when it comes to the siblings meeting their little sister or brother. The parents thought that

one should encourage the siblings to participate on their own terms, trust their ability to handle their own grief, take them seriously, and respect their standpoint. Older siblings can give expression to their needs, according to the parents, and no feelings, thoughts, or expressions should be taboo. The parents' advice to other parents was to view death as a part of life. Parents should rely on their sensitivity vis-à-vis their children's feelings and needs and try to make the situation as natural as possible. The following comments illustrate the parents' advice to respect the siblings' feelings:

He got to meet his sister and could decide himself whether he wanted to hold her. He chose not to do it, but he examined her closely, counting fingers and toes. (A mother who had lost her child in gestational week 35)

At last she had us know that she wanted to be alone with the baby, we had to close the door. What she did in there we don't really know, that's private, but she has told us that she was singing for him. So my advice is: Try to trust your child to find strategies to get through the process. (A mother who had lost her child in gestational week 34)

The parents stressed the importance of confirming siblings' grief and of being able to show how they feel themselves. Parents can explain how they feel, but siblings do not have to mourn in the same way. Parents should be open for different forms of expressions and the fact that everybody mourns in his or her own way. Confirming sisterhood or brotherhood was pointed out as important, too. Elder siblings must be allowed to feel proud—they have waited and got a beautiful, though dead, little brother or sister. It is important for them to be given the opportunity to tell others that they have become a big brother or sister and to talk about the little one—it helps them cope with their own grief and loss. The following comments illustrate the parents' advice to confirm the siblings' grief:

You should talk about the dead child with the older children because it's not only the parents who are waiting for the baby and are involved during the entire pregnancy; the sibling is just as curious about the brother or sister that's on the way and has many expectations. (A mother who had lost her child in gestational week 39)

Even if their little sibling is dead, it is still their sibling. (A mother who had lost her child in gestational week 28)

Adapt to the siblings' age. This subcategory covered 131 statements about the children's age, maturity, and internal resources determining the level of participation in processes surrounding a stillborn sibling and the leave-taking from that sibling. Older children will have to take their own time to say farewell to their sister or brother. According to the parents, the siblings' age and level of maturity also determine how and to what extent the loss needs to be concretized. Play is to be encouraged because children express and model their grief through play, which allows them to process their experiences, thoughts, and feelings. Other forms of expressions that should be encouraged are singing, drawing, and telling stories, the parents maintained. The following comments illustrate the parents' advice on encouraging the siblings to adapt to their grief in their own way, according to their level of maturity:

It is weird for a little child to understand the loss of something that hasn't existed; it's important therefore to make the loss as concrete and tangible as you can. (A mother who had lost her child in gestational week 26)

It's important that they get to play, our daughter has played giving birth and funeral etc. (A mother who had lost her child in gestational week 28)

A comparison of the parents' pieces of advice according to the gestational week when the stillborn baby was born showed that it was more common for parents with a baby stillborn after 28 gestational weeks to give advice falling within the subcategories "Experience the stillborn baby" ($p = .02$) and "Get siblings involved" ($p = .01$) compared to parents whose baby died in weeks 22–28.

DISCUSSION

"Make the stillborn baby and the loss real for the siblings" was the parents' message to other parents who have lost a child before birth and have older children. The parents advised that the siblings should be allowed to meet and experience their little sister or brother and to participate in the leave-taking in accordance with the siblings' feelings, resources, and circumstances.

The importance of letting siblings experience their stillborn brother or sister and of inviting them to participate in the chain of events, to a degree that corresponds to their level of development and their own resources, has been pointed out in several studies (Black, 1996; Dyregrov, 2008; Wilson, 2001). The parents in our study reported good experiences of letting siblings meet their stillborn sister or brother and getting involved. The parents thought that the elder sibling should see, hold, and touch the baby, which is also recommended by the literature in the field (Black, 1996; Dyregrov, 1989; Wilson, 2001).

Each child should have the support of a caring adult to answer questions and take care of him or her during the times the parents are emerged in their own grief. The parents can be involved in the process of choosing the support people, or other family members can take on the task if parents are not able at that time. This suggestion is in line with other researchers' recommendations (Black, 1996; Dyregrov, 1989; Giovanola, 2005). The siblings' participation in the funeral ceremony can be a basis for future talks during their adolescence. Black (1993) and Dyregrov (1989, 2008) recommended, like the parents in our study, that the children leave a symbolic gift to their stillborn sibling in the coffin. Leaving a symbolic gift is described by Dyregrov (2008) as a concrete action in siblings' mourning that can help them to bid farewell to their little sister or brother.

Advice from parents who lost a baby after gestational week 28, as compared to parents whose stillborn child was born between weeks 22 and 28, was more often about letting older siblings experience the stillborn baby and participate in what is going on. This advice can be related to the fact that a child who dies early in pregnancy is smaller and that its sibling may not have grasped yet that he or she was to be a big brother or sister, which is why the parents may be more restrictive with advice concerning meetings and participation (Bowlby, 1969; Klaus, Kennell, & Klaus, 1995). A larger share of the parents with a baby lost after gestational week 28 advised others to let siblings see and hold the baby. It is possible, and not only because the parents gave advice based on their own experiences, that more preparation by parents and health-care staff is needed when a sibling is to meet a stillborn baby born early and with a low birth weight than when the sibling is to see and hold a larger baby with a higher birth weight. This viewpoint, together with the siblings' age, is linked to another important piece of advice from the parents

in our study: Do not force siblings to get involved; rather, invite them to do so in an encouraging manner. The parents thought that the siblings' age, level of maturity, feelings, and mental resources must determine the degree of participation in the leave-taking. This advice is confirmed by Davies (1995), who reported that the siblings' developmental stage and prerequisites, including their conceptual understanding of death, are important factors for how and how much they should be involved.

In order to enhance the siblings' understanding of what has happened to their family, the parents in our study advised other parents to provide siblings with accurate and honest information and to invite discussions that are suitable for the siblings' frames of reference. This advice can be related to Dyregrov (2008) emphasizing the importance of giving the same information to all family members in order to improve the communicative climate between parents and children. Several researchers have pointed to the importance of communication between parents and siblings as a way of helping the children in their grieving (Dyregrov, 2008; Fanos, Little, & Edwards, 2009; Kempson, Conley, & Murdock, 2008; Kreicbergs et al., 2004; Wilson, 2001).

The parents in our study rarely gave advice concerning professional support for the siblings. Dyregrov (2008), however, recommended that health-care professionals, counselors, and priests are key persons who can advise on how open and honest communication can be achieved in a family when discussing difficult topics such as bereavement.

Some parents in our study thought that participation in certain events should be repeated; a child may feel the need to see and hold the stillborn baby on several occasions. Information and communication may have to be repeated, too, and be adapted to the siblings' age, needs, and understanding. Stroebe and Schut's (1999) approach to dealing with loss corresponds with this advice. They described the double approach of trying to evade and confronting a loss. Such an approach gives the grieving child the possibility to measure out the grieving process over time (Stroebe & Schut, 1999), because children mourn according to their age-related level of development (Black, 2005; Dyregrov, 2008; Mahon & Page, 1995; Randall, 1993).

Strengths and Limitations

The strength of this study is the large amount of advice that has been collected and described. The

advice comes from a large group of parents who experienced a stillbirth while, at the same time, they had other children.

One study limitation is that the parents' advice cannot be related to the siblings' age at the time of the stillbirth because this information was not asked for in the questionnaire. Furthermore, the self-recruitment approach probably implies that mostly parents who were especially interested in the topic shared their advice, particularly parents with positive experiences of siblings meeting the stillborn baby. Another limitation is not being able to systematically interrogate similarities and differences between respondents' demographic data in relation to the open question that we analyzed. These limitations severally limit our conclusion of this study.

The parents participating in the study had experienced a stillbirth between the years 1961 and 2010 (median 2004), a long period during which attitudes and customs concerning the involvement of siblings in stillbirths and children's grief have changed (Dyregrov & Dyregrov, 2008). This long period could be seen not only as a limitation but also as a strength because the participating parents acquired wisdom and, therefore, could offer a broader perspective from having a few more decades of life experiences. However, the median year (2004) indicates that most of the experiences reflect current customs and attitudes.

We found significant differences for two of the sub-categories, "Experience the stillborn baby" and "Get siblings involved," which concern advice from parents with stillbirths before and after gestational week 28; however, these findings should be approached with care because they are a consequence of our interpretation of the answers to the open question studied here. On the other hand, in order to strengthen credibility, data collection and analysis are described in detail. In addition, our results are in accordance with previous research in the field, which further increases the trustworthiness of this study (Polit & Beck, 2004). Therefore, despite the limitations of our study, we think that the advice given by parents to other parents and reported here is a valuable contribution to the support of siblings of stillborn babies.

CONCLUSION

Parents advise that siblings of a stillborn baby should be allowed to experience their little sister or brother and that siblings should be invited to participate in a way that respects their feelings and resources.

CLINICAL IMPLICATIONS AND FURTHER STUDIES

Adequate support for families whose baby dies requires close listening to the parents themselves and familiarity with successful programs of helping families deal with grief. Professional caregivers must be able to acknowledge parents' feelings of shock, guilt, and grief, to recognize the importance of the parents' memories of the birth and the baby, and to help them sharpen the reality of the death. Professional caregivers must provide informed choices for parents, enabling them to make their decision about sharing this experience with their children. The siblings' involvement should be led by their parents, and professionals can assist by giving advice. They can usefully be proactive in their approach to facilitate and encourage the involvement of siblings so that siblings can meet their brother or sister. Professionals can use the advice presented here in discussions with the parents of a stillborn baby who also have older children.

As to possible further studies, the consequences for children losing a little brother or sister need to be studied more from the perspective of those children. Investigating children's relationships with unborn siblings is another area that deserves more attention.

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